ORIGINAL PAPER

Preliminary study of the effect of the web application on caregiver burden in dementia and behavioural and psychological symptoms of dementia

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ABSTRACT

This study aimed to investigate if our web application could be a viable intervention for providing caregivers with information on resilient coping strategies for the reduction of their burden, thereby leading to the alleviation of behavioural and psychological symptoms of dementia (BPSD). We recruited outpatients with dementia and informal caregiver dyads at Nagoya University Hospital from April 2022 to October 2022. The caregivers were asked to have the web application installed on their smartphones during the study period and answer the following two self-administered questionnaires once a month for 3 months: (a) Abe's BPSD Score (ABS), which assesses BPSD, and (b) the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI) score, which measures caregiver burden. Thirteen patients and informal caregiver dyads were enrolled in this study. The caregivers exchanged information on the care of patients with dementia in the virtual community using the web application during the study period. Upon entry, J-ZBI scores were correlated with ABSs (r = 0.65). Linear mixed-effects model revealed the average J-ZBI scores decreased over time with significance (p = 0.013), however, the average ABSs did not change during the study period. This is the first study to show that our web application reduces caregiver burden. However, to confirm the efficacy of our web application, further investigations are required.

Keywords: caregiver, burden, BPSD, dementia, application

Abbreviations:
BPSD: behavioural and psychological symptoms of dementia
ABS: Abe's BPSD Score
J-ZBI: Japanese version of the Zarit Caregiver Burden Interview

INTRODUCTION

In Japan, in 2009, a national survey of dementia conducted by the Ministry of Health, Labor and Welfare of Japan reported that the prevalence of dementia was more than 15% among individuals aged ≥65 years.[1] Based on this data, the number of individuals with dementia aged ≥65 years in 2012 was estimated to be 4.62 million nationwide; by 2025, this number is expected to reach more than 7 million.[2] As of 2019, there have been 1.19 million individuals aged ≥65 years who are considered to have conditions requiring dementia care.[3] Thus, the Japanese government aims to disseminate and establish community-based integrated care systems in all local municipalities by 2025, where a care package of housing, health care, long-term care, preventive care and support for a living can be provided[4] under the public long-term care insurance (LTCI) scheme launched in the year 2000.

In these circumstances, families of individuals with dementia are expected to be the major source of informal caregiving. In Japan, in approximately half of the cases, any of the family members have been reported to be primary caregivers.[5] Despite being anticipated to take this role for approximately 15 years,[6] most primary caregivers have neither professional knowledge nor sufficient training to cope with the various behavioural and psychological symptoms those patients with dementia exhibit. Therefore, they are reported to be significantly more likely to experience symptoms of depression and anxiety due to a combined physical and psychological stressor,[7] which comes from caregiver burden defined as a multidimensional response to the physical, psychological, emotional and financial toll of providing care,[8,9] than non-caregivers. Therefore, informal caregiver burden of patients with dementia has become a serious concern.

Based on our understanding that caregiver burden has been observed to be alleviated by interventions, including psychoeducational intervention for addressing caregivers' well-being, providing them with information on their role and available resources,[10-12] we developed the web application, where the participants anonymously enjoyed their conversations and exchanged information on how to resolve the challenges they experienced in providing care for their patients with dementia.[12]

In this study, we hypothesised that the web application provides easier access to any information that may help caregivers in coping with caregiver burden through the conversation in the online virtual community, thereby reducing the caregiver burden and alleviating the behavioural and psychological symptoms of dementia (BPSD) through their generated emotional leeway.

METHODS

Study participants

From April 2022 to October 2022, we recruited outpatients with dementia and informal caregiver dyads attending the geriatric outpatient clinic of Nagoya University Hospital in Nagoya, Japan, and several formal caregivers, who belonged to other institutions. Dementia diagnoses were made on the basis of the Diagnostic and Statistical Manual of Mental Disorders, fifth edition criteria. Exclusion criteria included participants who did not have a smartphone or could not use it by themselves. After written informed consent was obtained from all informal caregivers and some patients with dementia if they could understand it, we monitored them for 3 months after the entry. The required sample size was calculated to be 30 with the sampling error being within 20%. The study protocols were approved by the Ethics Committee of the Nagoya University Graduate School of Medicine and registered as No. jRCT1042210111.[13]

Web application

We developed this web application (Fig. 1),[12] which consisted of mainly two components: One provided opportunities to learn what dementia and BPSD are, information on the care of patients with dementia, the community-based integrated care systems and miscellaneous topics related to caregiving. Another provided the virtual space, where patients with dementia and their caregivers could anonymously exchange information on how to care patients with dementia and how to cope with caregiving stress through chat with other participants.[12] The web application was installed on each caregiver's smartphone.

They can chat with others freely on this interface.
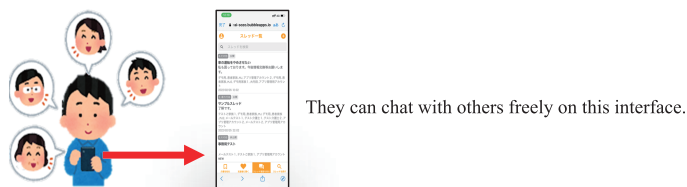
Fig. 1 Concept of web application system
Web application build a virtual social network, where patients with dementia and their caregivers can anonymously connect with other patients and caregivers and get information on care.

Baseline

Upon entry, a structured questionnaire, which includes questions on demographic characteristics, types of dementia, level of care-need certification and the period during which they provided care to their patients with dementia, was used through face-to-face interviews lasting for approximately 15 min by two research nurses.

Three months after entry

To assess the degree of BPSD of the patients and their caregiver burden, we asked the caregivers of the patients with dementia to answer Abe's BPSD Score (ABS) and the Japanese version of the Zarit Caregiver Burden Interview (J-ZBI), respectively. They were evaluated using these questionnaires once a month at four points: 'before', before using the application; 'after 1', 1 month after; 'after 2', 2 months after; and 'after 3', 3 months after.

Other participants

There were 43 unrecruited individuals who showed keen interests to join this virtual community since our study has been introduced by multimedia. We decided to include them because we thought they may facilitate the conversation held in the virtual community. They were not counted as study participants but were considered as informal caregivers of patients with dementia.

Outcome measurements

ABS assessing BPSD has 10 items allotted by an already-weighted score (ranging from 1 to 9) based on the frequency and severity, and the full score is 44 points.[14] The J-ZBI has 22 questions with four choices for each item to measure the subjective burden among caregivers of patients with dementia, and the total score is 88 points.[15] The cut-off score is 25 points. Those with a score of <25 are considered to have a lower risk of developing depression.[16]

Statistical analyses

We calculated Spearman's correlation coefficient and drew a fitter line between ABSs and the

J-ZBI scores, assuming a linear relationship. The inter-point change in ABSs or J-ZBI scores was estimated using linear mixed-effects model with unstructured variance–covariance matrix, random intercept and random slope for each individual, adjusted for sex and J-ZBI scores or ABSs at the four points. Differences in the means of ABSs at 'before' were evaluated using Student's *t*-test after dividing the patients into two groups by a cut-off score of 25 of J-ZBI at 'after 3'. Calculations were performed using Stata version 17 (StataCorp, College Station, TX, USA).

RESULTS

In this study, 15 patient and informal caregiver dyads were recruited between April 2022 and October 2022; however, two dyads declined before answering the first self-administered questionnaire. To monitor the conversation held among the participants in the virtual community, seven formal caregivers voluntarily attended this study.

Table 1 The demographic and clinical characteristics of caregivers and patients (n=13)

| **Caregivers**		n
Gender	Male	2
	Female	11
Age	40–49	1
	50–59	4
	60–69	4
	70–79	3
	≥80	1
Duration of care (years)	less than 1	3
	1–2	2
	2–3	4
	3–4	1
	4–5	2
	more than 10	1
Patients with dementia		
Gender	Male	6
	Female	7
Age	60–69	1
	70–79	5
	≥80	7
Type of dementia[a]	Alzheimer's disease	9
	Cerebrovascular disease	1
	Frontotemporal lobar degeneration	1
	Mild cognitive impairment	2
Long-term care service[b]	Commuting rehabilitation service	3
	Commuting for care	4
	Home-visit nursing care	1
Long-term care/support need[c]	Independence	3
	Requiring support level 1	2
	Requiring support level 2	1
	Requiring long-term 1	3
	Requiring long-term 2	2
	Requiring long-term 3	1

[a] Multiple choice is allowed.
[b] Five patients did not use any long-term care services.
[c] One patient was applying at the entry.

Of the participants, 11 of the 13 caregivers were female and 9 of the 13 patients were diagnosed as having Alzheimer's disease (Table 1). The duration of care of all caregivers was <5 years, except one who provided care for more than 10 years. Five patients did not use any services provided by the LTCI. Regarding the care-need certification, all but one of patients were certified as being below level four. The one patient was applying at the entry. All caregivers could use the web application installed on their smartphones for the study period. During this study, one of the registered caregivers did not answer ABS, eleven and three caregivers completed the J-ZBI and ABS four times, respectively; one caregiver took five months to complete ABS. Five caregivers had <1-month intervals after some point.

The correlation between the J-ZBI scores and ABSs at 'before' (r = 0.65) is shown in Figure 2. As shown in Figure 3A, the average scores of the J-ZBI significantly decreased following the use of the web application (p = 0.013). However, the average ABSs did not show significant decreasing trend (Fig. 3B).

Subsequently, we divided 10 caregivers who answered ABS at 'before' into two groups using a cut-off J-ZBI score of 25 at 'after 3'. Those whose J-ZBI scores were <25 at 'after 3' tended to have lower average baseline ABSs (12.0 vs 2.75, p = 0.14).
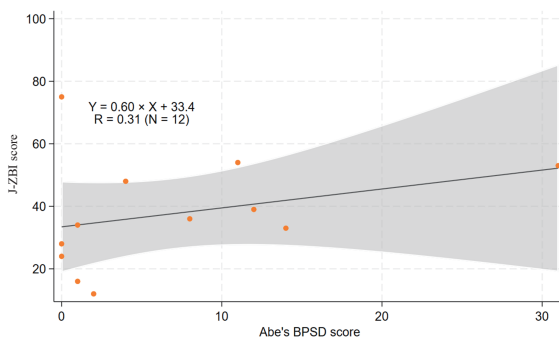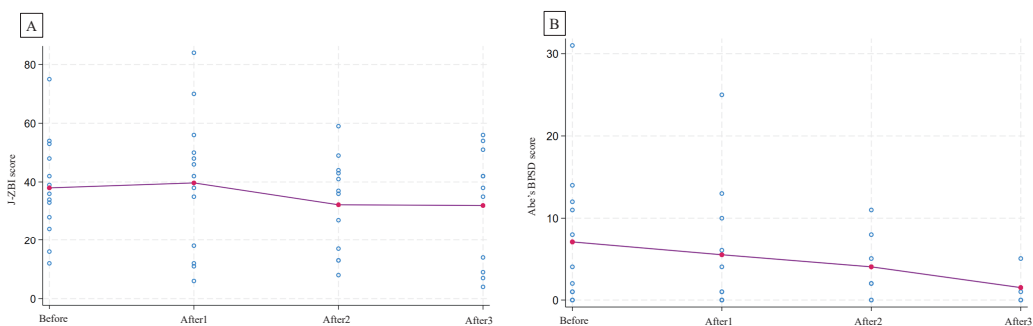

Fig. 2 The correlation between the J-ZBI scores and ABSs
Solid line expresses best-fitting straight line to the J-ZBI scores-ABSs with 95% confidence (gray area).
BPSD: behavioral and psychological symptoms of dementia
ABS: Abe's BPSD Score
J-ZBI: Japanese version of the Zarit Caregiver Burden Interview

Fig. 3 Effect of web application on caregiver burden and BPSD

Fig. 3A: Line graph is showing the average scores at each point. The inter-point change in the J-ZBI average score was estimated to be –3.38 (95% confidence interval: –6.62 to –0.15) by linear mixed-effects model, adjusted for sex and ABSs at each time point.

Fig. 3B: Line graph is showing the average scores at each point. The inter-point change in the average ABSs was estimated to be –0.50 (95% confidence interval, –1.39 to 0.43, p=0.30) by linear mixed-effects model, adjusted for sex and the J-ZBI scores at each time point.

BPSD: behavioral and psychological symptoms of dementia

ABS: Abe's BPSD Score

J-ZBI: Japanese version of the Zarit Caregiver Burden Interview

[a] One caregiver took five months to completed ABS four times.

[b] Five and four participants answered respectively the J-ZBI and ABS less than one month after the previous point.

DISCUSSION

This study aimed to examine whether our web application could palliate caregiver burden and BPSD by inviting caregivers to a virtual community for mutual communications. Our findings indicated that exchanging information with peers in the virtual community could alleviate caregiver burden although not the BPSD of their patients with dementia. Our post-hoc analysis showed that for those whose J-ZBI scores were <25 at three months after the entry, their baseline ABSs upon entry were lower than those whose ZBI scores were ≥25 without statistical significance.

Our web application was developed as a non-pharmacological intervention, including psychoeducational intervention for caregivers. Psychoeducational intervention is the most frequently used intervention and includes lectures, discussions, written materials and accessing online resources. Therefore, psychoeducational intervention would help caregivers understand why problematic symptoms (eg, BPSD) are presented and how to deal with them. Dementia café in the real world, by which our application was more or less inspired, is close to our current idea of a method for psychoeducational interventions. Previous studies have reported that the participation of patients with dementia and their caregivers in a dementia café promoted social inclusion and prevented isolation by sharing information regarding the care of patients with dementia.[17,18] However, some dementia cafés have no separate space for individual counselling and free conversation.[19] In contrast, exchanging information inside the virtual community can be performed behind the veil of anonymity. In addition, it could provide appropriate opportunities, where family caregivers talk about their complaints at ease without being notified by their patients with dementia; therefore, this can be considered as an advantage of our web application. In particular, sharing the burden of caregiving with others may help caregivers mitigate the psychological distress by feeling 'I am the only one suffering'.

The family care support projects are listed in the Chapter 6 of the Long-Term Care Insurance Act. However, there is no sufficient number of caregiver support projects in Japan. Even if there

is, the projects seem not to be efficacious for reducing caregiver burden, compared with the National Carer Strategy in Australia,[20] which supports caregivers to live their lives with dignity. The National Carer Strategy contains six priority areas for improving outcomes for caregivers.[20] Especially, three priority areas ("Information and access", "Services for carers" and "Education and training") seem to be related to psychoeducational intervention. Therefore, to decrease the caregiver burden, it is necessary to improve access to information and provide useful solutions for alleviating caregiver burden. We believe that our web application could embody the concepts of the three priority areas above by exchanging information on care with formal and informal caregivers in the virtual community and hope this web application will be helpful to the caregiver support project in Japan. Although our post-hoc analysis showed a non-significant result, we could not deny the possibility that their caregiving burden could easily improve using our web application only if BPSD were not severe upon entry.

Consistent with previous reports,[21,22] caregiver burden was correlated with BPSD severity upon entry. The alleviation of BPSD has been reported to reduce caregiver burden.[23,24] Conversely, we hypothesised that our approach of providing a virtual community would palliate BPSD by offering an emotional leeway to caregivers. However, only three caregivers completed answering the questionnaire to assess BPSD at the given periods (4 times). Moreover, considering that it may take much longer time to control BPSD, it is possible that the duration of our study was too short to make a plausible interpretation of the results. Whether controlling caregiver burden can alleviate BPSD or not remains intriguing, therefore worth investigating in our future studies.

There were some limitations of the present study. The number of participants was relatively small, compared with the required sample size. Factors which could affect our results, such as the use of antipsychotic drugs and the degree of dementia, were not considered as the adjustment factors because they were deemed to be proxy variables affecting long-term care/support, which had little variance in this study. As we focused on providing virtual community accessible anytime on the application for exchanging or sharing information among the caregivers, we did not record the log for assessing the frequency and the time used by each applicant. In addition, this study was an interventional study without controls, which could not confirm the efficacy of the web application. However, considering that several individuals have shown interest in joining this virtual community since our study has been introduced by a newspaper and broadcasted on television programs, we believe that our study has a potential of leading to further large-scale investigations with more convincing design such as RCT. In fact, some individuals who have shown keen interest facilitated the conversation by voluntarily joining the virtual community and exchanging information and their experiences in the care of patients with dementia with the study participants. Nevertheless, since their patients were not outpatients of our study setting, we could not include them as study participants.

Five caregivers answered the J-ZBI less than one month after the previous point. There were three of them whose J-ZBI scores changed less than 5 in less than one month. However, two of the three showed their J-ZBI scores already changed by about 20 at the previous point, compared with the scores upon entry. Therefore, there was a possibility that the short intervals between some points could have affected the evaluation of web application on caregiver burden.

In conclusion, our study showed that our web application, as a psychoeducational intervention, reduced caregiver burden. Then, we think that this application could be one of useful interventions for supporting caregivers of patients with dementia in Japan. However, whether or not the reduction of caregiver burden alleviates BPSD remains unclear. The larger interventional studies with control groups are required to confirm the efficacy of the application and clarify the causality between caregiver burden and BPSDs.

ACKNOWLEDGMENT

CONFLICTS OF INTEREST

FUNDING

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